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ABSTRACT

This monograph presents excerpts from discussions with participants in the Pennsylvania Developmental Disabilities Planning Council 1990 retreat, which focused on the creation of effective safeguards for people with developmental disabilities. The discussions note: the increased vulnerability of such people to neglect, abuse, and mistreatment; the shortcomings of unregulated relationships between people with disabilities and their caretakers; and the limitations of systematic efforts to keep people safe through professional, bureaucratic methods. David B. Schwartz in "Quality Assurance in the Asylum" looks at historical aspects of this question. The discussion first focuses on identifying what makes people vulnerable (e.g., lack of power, isolation, lack of alternatives, poverty). Next the contrasting approaches of administrative regulation and related legal advocacy versus lifesharing and other personal commitments are analyzed in terms of their contributions, limits, costs, and effectiveness. Covered next are strategies for increasing safety (such as supporting the contribution of families and friends) and options for actions that make families more powerful, reduce isolation, demonstrate effectiveness, yet minimize the costs of regulation. (DB)

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perspectives
On Community Building
Discussion Report

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What Can We Count On To Make and Keep People Safe?

Perspectives on creating effective safeguards for people with developmental disabilities

from discussions with participants in the

Pennsylvania Developmental Disabilities Planning Council Annual Retreat

edited by
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January 1990

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Contents

Thanks 1

The Question: *What can we count on to make & keep people safe?* 2

❒ Quality assurance in the asylum 3

Concerns that shaped the context of the discussion 4

The agenda 7

What makes people with disabilities vulnerable? 9

❒ What keeps Joanie safe? 16

❒ How regulatory control expands 18

Analysis of contrasting approaches 19

Administrative regulation & related legal advocacy 20

Lifesharing & other personal commitments 22

❒ Competing social tools 24

❒ The loss of spirit 26

Strategies for increasing people's safety

Work for social change 27

Support the contribution of family & friends 28

Work on service system issues 29

Support the contribution of service workers 30

❒ Accounting & reducing the costs of regulation 31

Options for action

To make children safer 33

To make adults safer 34

To minimizing the costs of regulation 35

❒ These are selections from background papers used by participants in the discussion.

perspectives

On Community Building
Discussion Report

Discussion reports in the Perspectives on Community Building series summarize group meetings on issues that concern those who are working to increase the presence and participation of people with developmental disabilities in the neighborhoods, workplaces, schools, and associations that constitute community life. Meetings include people with different interests and points of view: people with developmental disabilities, family members, people who provide and manage services, people who make policy and manage service systems, and others who work for stronger, more inclusive communities.

Discussion focuses on deepening understanding of an important theme and creating options for action rather than on making specific plans and decisions. The process emphasizes exploration of different perspectives on complex situations rather than defining consensus positions. So points in the summary may conflict with one another. Neither the editors nor all participans necessarily agree with each point and the summary does not represent an official position of the group that sponsored the meeting.

Discussions usually happen as events in the context of change efforts; sponsors often schedule them as retreats, search conferences, or reflection days. Participants typically know at least some other people at the meeting, and some participants get involved in planning and following up the meeting.

A facilitator and recorder guide the group's work: negotiating an agenda and discussion groundrules, managing the group process, and recording and summarizing the discussion. The recorder prepares and circulates a written summary from large graphic displays and audiotapes made during the meeting. The summary preserves participant's own words and images and organizes their contributions around themes identified during the discussion. The Perspectives paper is edited from the meeting summary, from participant's comments on the summary, and selections of other materials shared by people present. The editor's introduction and comments are not reviewed by participants.

Material from the discussion is between the lines on pages like this

Editor comments & selections from other materials are on plain pages like this. Selections are signed.

Preparation of this chapter was supported through a subcontract from The Center on Human Policy, Syracuse University for the Research & Training Center on Community Living. The Research & Training Center on Community living is supported through a cooperative agreement (Number H133B80048) between the National Institute on Disability & Rehabilitation Research (NIDRR) and the University of Minnesota Institute on Community Integration. Members of the Center are encouraged to express their opinions; these do not necessarily represent the official position of NIDRR.

The discussion summarized here took place at the Annual Retreat sponsored by the Pennsylvania Developmental Disabilities Planning Council on 11-13 November 1988 in Harrisburg. Members of Speaking for Ourselves (a self-advocacy group), activists with physical disabilities, advocates who are family members, disability rights attorneys, people living in intentional community, and people who provide services and manage service systems joined council members to explore options for increasing the security of people with disabilities.

Thanks

To participants in the retreat for their sustained and thoughtful discussion and their willingness to listen to people with differentpoints of view on a complex and difficult issue.

Special thanks to the retreat planning committee —Mark Friedman, Harry Guise, Jerome Iannuzzi, and David Schwartz— who risked the discomfort of an open-ended agenda; to those who prepared reflections on the conference theme— Steve Eidelman, Lucy Hackney, Roland Johnson, Illene Shane, Rud Turnbull, and Helen Zipperlin— for modeling openness, self-criticism, and careful thinking about their deep concerns; and to Chris Barton for setting the whole discussion to music.

Throughout this paper are excerpts from a manuscript, "What really keeps people with disabilities safe in society?" prepared by David Schwartz in September 1988 and selections from materials sent to participants before the meeting.

The Question

The question —*What can we count on to make and keep people safe?*— frames an important perspective on the continuing work of building communities that offer people with developmental disabilities full and dignified lives. It arises from a realization of the vulnerability to neglect, abuse, and mistreatment risked by people who require substantial, long-term assistance to take and keep their rightful place as citizens. It is shaped by a sober recognition of the shortcomings of unregulated relationships between people with disabilities and their caretakers and the limitations and ironic effects of systematic efforts to keep people safe through professional, bureaucratic methods. Left to their own devices, a frightening number of care providers act inhumanly. But increasing investments in formal means to regulate these relationships don't proportionally increase confidence in people's safety. Indeed formal systems seem to weaken the spirit of commitment necessary for caring relationships to thrive. Discussion is animated by acknowledgement of the desirability and necessity of action to increase people's safety by both strengthening the ties of community and making necessary assistance more relevant and effective.

To increase safety:
- Strengthen community.
- Improve needed assistance.

As the note on the next page shows, efforts to ensure the safety of people who rely on services have an instructive history. Many of today's approaches to improving quality through policy, training, hands-on management, and external monitoring would be familiar to nineteenth century asylum keepers. Then, as now, their insufficiency raises a troubling issue. Can it be that the very design of well managed settings that meet every need frustrates our attempts to embody our good intentions? Could it be that the community services we have carefully developed share too many characteristics with earlier, now discredited approaches? And if so, must people with developmental disabilities accept the built in limits of total environments as the best available compromise in a dangerous world? What strategies offer ways to constructively engage these questions?

"It should be a sobering reminder to us that, when the pioneers in our field undertook their task, despite the greatest good will and thoughtful deliberation they led to the development of modern institutional settings. In offering enormous benefits, their work led to loss of everything important to their beneficiaries."

–Burton Blatt

Quality Assurance in the Asylum

David B. Schwartz

The Willard Asylum for the Chronically Insane was founded in response to a social outcry over the mistreatment of "the insane" in county jails and almshouses in the nineteenth century. Dedicated staff and trustees worked unceasingly to better their condition. Yet barely were the opening celebrations over than Willard found that it was not itself immune to the persistent problems of abuse and neglect. It must have come as a discouraging shock to the idealistic founders.

"Before closing the doors for the night, attendants must see that the patients are comfortably in bed; and it is especially enjoined that they offer gentle and patient assistance to the feeble and aged, and leave all with a kind 'good night.'"
—Rules for attendants, Willard Asylum, 1869

The institutional planners were not naive. Practices to maintain the quality of care were built in from the beginning. Designed following the popular "Kirkbride plan," the asylum was built in two "wings" centered by the residence for the medical superintendent and his family. Knowing that the most "excited" patients were most likely to precipitate mistreatment from staff, it was apparently the practice at Willard to place the ward for that class in the building complex joined to the superintendent's apartments. It was easy to tour the wards unexpectedly. The Board of Trustees were no less vigilant; in their bylaws they entered the requirement that the facility be visited by a board member weekly. Yet despite these and other monitoring mechanisms, cases of abuse must have begun to occur. The first public sign of this came in an annual report to the legislature only six years after opening. In it an "experiment" was noted in which a "gentleman" of the vicinity had been engaged to tour the male wards daily and to report on the "demeanor of attendants toward patients," so that he might "provide a wholesome restraint" upon the behavior of attendants.

One must assume that this particular solution proved insufficient, for barely four years later resort was made to proposing a far more severe remedy. In that report the trustees and the administrator together asked the state legislature to pass a law making it a misdemeanor for an attendant to commit an assault upon a patient. Notice of the law was to be posted on every ward and in the very bedrooms of employees. A year later the annual report noted that the greatest danger to quality of care was still "undue severity" or neglect by attendants. Defending itself against public criticism in the use of physical restraint, the superintendent expressed hope that more thorough training for employees might develop their humanitarian inclinations and thus reduce the frequency to which restraint was resorted. The success of this approach is not known.

Whether in the garb of the New York state's present Commission on Quality of Care, the State Lunacy Commission, or that anonymous "gentleman" who walked the asylum wards a century ago, a lesson may be that the job of the monitor of quality and human rights is a constant one. It is when society loses interest in peering over the asylum wall that the fruit of inattention is really born. But even more importantly, those early asylum idealists had to learn through their own inevitable failure that, in Andrejs Ozolin's words: "even if institutions were put in the best working order, they would be intrinsically abusive at their best and their best would be virtually impossible to sustain." What seemed like the best plan, developed by the best people, had failed to fulfill its dream. Instead of "refuge" the word "asylum" would come in time to be an ultimate symbol of abandonment and despair.

"even if institutions were put in the best working order, they would be intrinsically abusive at their best and their best would be virtually impossible to sustain."

Concerns that Shaped the Context of the Discussion

The Pennsylvania Developmental Disabilities Planning Council's retreat planning committee expresses the history of the question in its invitation to a meeting to follow-up on the retreat summarized in this report.

The struggle to improve the lives of citizens of Pennsylvania with developmental disabilities has been a long and difficult one. Each step of progress: to gain admission of children with disabilities to school, to free people from life in institutions, to support people in their own communities, has come only as the result of unceasing work by many committed people.

While gains have often been frustratingly slow, and there are always many more needs to be met, there has usually been a sense of progress being made. People with most disabilities –especially with mental retardation– unquestionably have much better life opportunities than they did thirty years ago... Innovative approaches... [expand] opportunities in new ways only dreamed of a few years ago, such as adoption for children with special needs, flexible and "family-driven" support to families, real employment for people who formerly worked only in sheltered workshops, and many other areas.

In spite of such progress, however, there have been a number of recent signs that serious problems still remain and that new ones are appearing. Among these are:

- People with mental retardation being returned to institutions from community settings.
- Financial and staffing crises in community services.
- Reports of children with disabilities not being given full medical attention in hospitals, and rumors of newborns with disabilities being allowed to die.
- The discovery of high rates of psychotropic drug use in community programs.
- Continuing incidents of abuse and neglect in institutions, and emerging incidents of similar problems in some community residences.

While the picture is still unclear, a disturbing sense of concern about the welfare of people with disabilities seems to be increasingly heard from parents, advocates, government officials, and people with disabilities themselves. Such concerns are not unique to Pennsylvania, and if underlying problems do exist it is clear that they have been developing for some time. It is often easy to place blame, but hard to understand the true dynamics behind the issues involved.

Concern with ensuring security for people with developmental disabilities grows with accomplishment.

- Real progress challenges the devaluing notion that people must accept and adjust to second class status because of their disability. But progress has not freed even those people with disabilities it has reached from heightened risk of abuse, neglect, and mistreatment.
- Forty years of vigorous advocacy has shown both the promise and the limits of legislation and litigation. Landmark decisions establish the right to education and create the opportunity for some people to live outside institutions. However, the complex systems that embody these intentions accumulate problems so serious that some observers fear they are close to breakdown. Others note that solutions become barriers as, for example, they recognize the unintended segregating effects of the current special education sys-

tem. And the tools for resolving conflict don't always work swiftly or reliably.

- As the services have grown larger and more complex, the spirit of reform that shaped the community services system in its early years seems to have given way to more routine formal relationships. State agencies have invested substantially in regulations and enforcement mechanisms; provider agencies have invested substantially in compliance. This pattern of regulation and compliance provides a means of responding to undesirable situations, but it does not work to build better quality srvices–as Steve Eidelman, Deputy Secretary of Public Welfare for Mental Retardation notes.

The Pennsylvania community mental retardation service delivery system is extremely diverse and highly decentralized. It is administered by 45 separate local government units in partnership with over 300 private agencies serving over 43,000 persons annually.

The 1966 Mental Health and Mental Retardation Act places responsibility to set and enforce standards with the Department of Public Welfare. Department of Public Welfare regulations establish minimum standards for the provision of various services...

Though basic health, safety, and minimum program elements are maintained by enforcement of these requirements, it is commonly acknowledged that **enforcement does not constitute the most effective method to enhance quality** in community mental retardation programs...

Advocates, consumers and their families have historically been instrumental in advocating for the establishment of new and expanded services and have been vigilant overseers of the provision of services. The vitality of Pennsylvania's community mental retardation services system depends on the dynamic interaction between this partnership and an accepting community....

From: Department of Public Welfare (1988). Quality enhancement. *Mental Retardation Bulletin, #00-88-06*, p. 2. (Emphasis added)

- Despite the growth of investiment in services, an increasing number of parents of people with severe disabilities still feel the urgency of the same basic question that animated the pioneers of the parent movement for people with mental retardation: *What will insure my child's security when I am no longer able to do so?*
- A small but growing number of people share their lives and sometimes their homes out of a recognition that interdependence among people with socially visible differences offers the best hope of security for everyone in a dangerous world. The more public of these efforts –such as Camp Hill Kimberton Hills, the Orion Communities, and the International Federation of l'Arche–communicate in their daily living together a sense of security and support for every members' development that impresses even those who would not choose such a life for themselves. These settings raise a question about the service system's duty to regulate the safety and adequacy of people with disabilities' homes and workplaces, even if they do not accept public funds from the service system. And system interest in regulating these living relationships causes deep concern that the pattern of regulation and compliance will destroy the heart of lifesharing by introducing

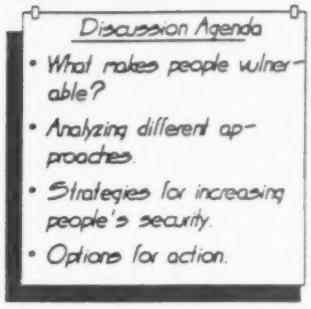
distinctions of inequality between "staff" and "clients." Finding ways for peoplewho are lifesharing and people with system management responsibility to learn from one another will strengthen both efforts.

Selections from John McKnight's argument for this position are on pp. 24-25.

- Some people have concluded that the pattern of increasing regulation amounts to using the wrong means to desirable ends. In their view, apparent improvements in the system make things worse by undermining the very fabric of community relationships essential to better lives for all people. Moreover, a rising tide of regulation drowns the spirit which must animate efforts to overcome injustice and exclusion.

Responses to the question –What ensures security?– provides a helpful complement to discussions about how to improve quality in human service systems. Participants in this discussion clearly identify that the qualities that offer people with disabilities security are the same qualities that define a good life: caring relationships, opportunities for participation and association, and power over the conditions of everyday life. The perspective offered here highlights some of the limits and costs of quality assurance systems and describes some of the other kinds of social change and systems change efforts essential to insuring that people with disabilities have the security offered by a good life in community.

The Discussion Begins


Discussion Agenda
• What makes people vulnerable?
• Analyzing different approaches.
• Strategies for increasing people's security.
• Options for action.

Wise decisions about how to increase the security of people with disabilities begin with improved understanding of the social conditions that increase vulnerability and careful analysis of the contributions, limits, costs, and conditions for effectiveness of the different types of available instruments. Understanding and analysis suggest possibilities for action.

When concerned people take action without taking time to clarify their understanding and account the possibilities and the limits of their tools, they miss opportunities and increase the chances of getting stuck in the unintended consequences of their action.

Clarence Sundram, Chairman of the New York State Comission on Quality of Care, identifies some of the consequences of acting too quickly on the assumption that more funding, more regulation, and more professional staff will create better environments for people.

Several years ago the Commission was conducting a study of the quality of care provided by community residences serving severely and profoundly mentally retarded persons in the New York City area. Many such residences had been established pursuant to the Willowbrook Consent Judgment and a large number of them had been converted into intermediate care facilities for the mentally retarded in an effort to increase the level of federal funding. One of the expected benefits of converting the residences into ICF-MR's was to enhance the level of clinical staff available to meet the needs of the residents. Yet, as we visited a number of homes, we were struck by the absence of any evident benefit to the residents from this increase in staff. It turned out that much of this newly found clinical staff time was consumed in preparing detailed treatment plans with long-term goals and short-term objectives, performing a variety of assessments, and filling the clients' records with a battery of tests and scores and indicators. Many of these procedures and processes were made necessary by Medicaid regulations. In essence, what this sounds like is that we went into the Medicaid program to get more money to hire more clinical staff to fill out the forms that the Medicaid program requires. What does this do to improve client care? When we commented on the paucity of direct services by these clinical professionals to the mentally retarded clients, we were told that the professionals had too much paperwork to be more involved in actually implementing the plans they were writing....

...[T]here seems to be something fundamentally wrong with the devotion of so much high priced and scarce clinical and professional staff time to the development of treatment plans that no one has the time to implement. For whose benefit are we doing this?

...[E]ffective regulation requires the ability to influence internal behavior with organizations to produce desired outcomes. When regulators do not know how to define the desired outcomes, their strategy often is to take complex problems and break them down into smaller sub-problems and focus on developing detailed regulatory specifications that attempt to control internal behavior of staff without reflection of the effect of these behaviors on outcomes. Both the regulator and the regulated know that the underlying problem is not being addressed but rather that elaborate games are being constructed. If the regulatees are seen by the regulators as always trying to find loopholes, then the duty of the regulator is to plug up such loopholes ahead of time. This leads to myriads of specifications, since regulatees are innovative in finding loopholes. As soon as a pile of specifications becomes high, the regulatees can mount their attack; namely, that they are swamped with regulations and specifications and paperwork. The regulators in turn will insist that they have no alternative. But over-regulation can miss the target in both directions.

from: Regulation – Have we all gone mad? *Quality of Care*, September-October, 1987, p. 6.

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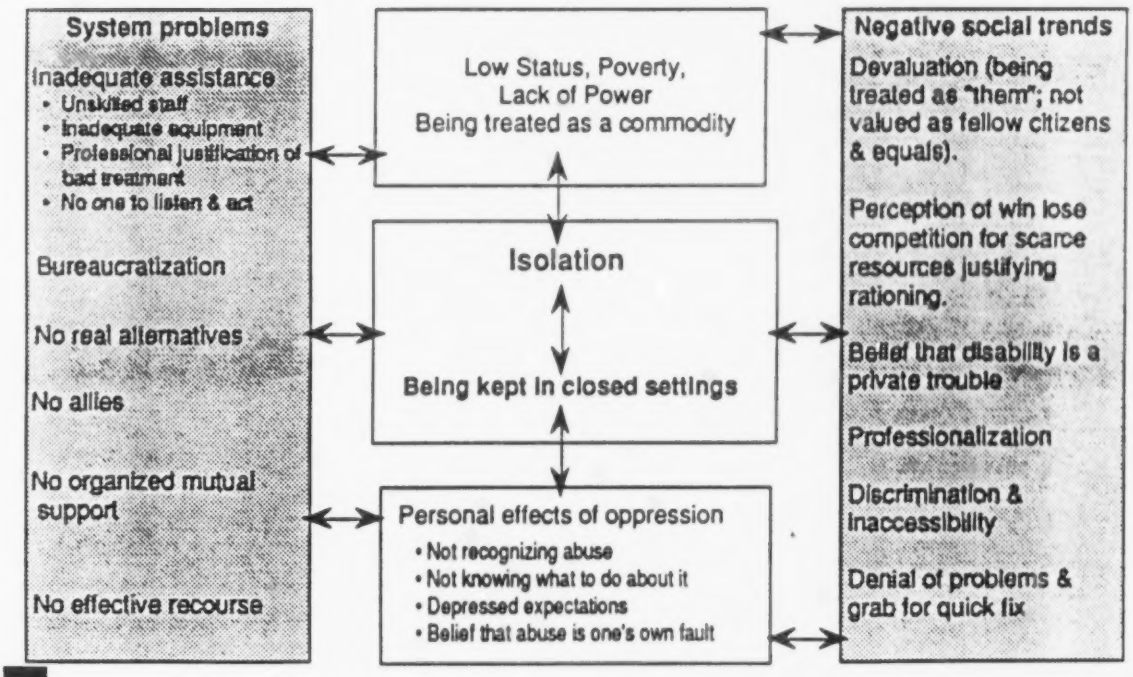
See pages 9-15.

This diagram below sumarizes discussion of the sources of people's vulnerability. It suggests important considerations for those who want to make people more secure:

- No single path leads to greater security. Positive action can and should address each condition. Different concerned people may be drawn to work on different conditions; none can claim dominance.
- Problems in one area will hinder efforts to address another. For example, efforts to increase people's options for recourse may be severely limited by the built-in inadequacies of closed settings.
- Focus on just one area can make people less secure. For example, decreasing bureaucratic controls over settings in which people are isolated and powerless is risky. This creates dilemmas.
- Failure to honor the capacity of people with disabilities to influence their own destinies underlies these conditions. Regardless of the focus of work, people with disabilities themselves should be actively involved in decision making.

What Increases People's Vulnerability?


System problems
Inadequate assistance
• Unskilled staff
• Inadequate equipment
• Professional justification of bad treatment
• No one to listen & act
Bureaucratization
No real alternatives
No allies
No organized mutual support
No effective recourse
Low Status, Poverty, Lack of Power
Being treated as a commodity
Isolation
Being kept in closed settings
Personal effects of oppression
• Not recognizing abuse
• Not knowing what to do about it
• Depressed expectations
• Belief that abuse is one's own fault
Negative social trends
Devaluation (being treated as "them"; not valued as fellow citizens & equals).
Perception of win lose competition for scarce resources justifying rationing.
Belief that disability is a private trouble
Professionalization
Discrimination & inaccessibility
Denial of problems & grab for quick fix

8

What Makes People with Developmental Disabilities Vulnerable?

❒ People with disabilities share the same vulnerabilities as everyone else in our society with even less power to deal with them. We are all vulnerable to unsafe streets, air and water pollution, ineffective transport, and a growing number of other threats right up to nuclear war.

Lack of power

- No one has the power to control all the threats to safety and well being. But people with disabilities typically have a much smaller area of power over the environments they live in than the rest of us. At the extreme, some people with disabilities have no time and place which is their own; they are always under someone else's supervision and control. Ironically, our best efforts to insulate people from the threats of the outside world have isolated them. To increase safety we have created places that have closed in upon themselves and deprived people with disabilities of the contacts, information, and power they and their families need to stay as safe as possible. To protect people we have made rules and regulations that effectively undermine staff people's ability to use their common sense. And even all these rules don't guarantee staff will treat people with common decency.
- Some risk, some suffering, is integral to our common humanity. It's impossible to defend against it without destroying the fabric of human life. But without vigilant and vigorous protection, people with disabilities are far too often neglected and abused. This is the dilemma we face: How do we collectively protect people without patronizing them or destroying their opportunities?

❒ There are two ways people with disabilities get hurt: actively, when somebody hurts you; and passively, when something you really need isn't there or doesn't work. What you need may be just for you —like a special kind of brace— or it may be something that benefits lots of people —like physically accessible environments.

Isolation

❒ People with disabilities are vulnerable when they are isolated.

Institutionalization

❒ There has been so much talk about deinstitutionalization that some people might think it was finished. We have to keep everyone aware of the continuing reality of institutionalization. Institutions aren't the only bad places, but they are bad and they are still there and their budgets are still growing. All the people aren't out yet; there are still 12 and 13 year old boys and girls there. And every institution isn't a state institution. People with disabilities are institutionalized in private facilities and nursing homes and jails.

Oppression& its personal effects

❒ Some people with disabilities are abused or neglected and think they deserve no better. People with disabilities are safer when they know for themselves what abuse is and what to do about it. This means more than just information; it means helping people sort out their expectations, taking responsibility for what they can do, and learning to deal with the anger and depression that arise from being oppressed.

- Groups like Speaking for Ourselves* can help many people with disabilities get a sense of what they deserve and support them to get it. Parents of children with disabilities also need group and organizational support.
- Access to other people with disabilities who have an effective sense of outrage and who can be models of how to live well with disability have been very important to many people.
- Ways to get people who otherwise wouldn't know people with disabilities, like Citizen Advocacy, help, especially when a person's disability makes it hard for the person to speak for him or her self or when a person is very isolated.
- Sometimes people need a good lawyer.

Inadequate settings & equipment

❒ Some people are in places that are physically unsafe.

❒ Lots of ramps and curb cuts aren't well made.

❒ Some people either lack equipment they need or have equipment that isn't safe. This can be easy to see —as when a person's wheelchair looks rickety. Or it can be harder to spot —as when a person isn't positioned right in a wheelchair that looks OK.

No recourse

❒ People are more vulnerable when there are no effective means of recourse.

- Some people with disabilities never see anyone but the people who perpetrate abuse. The supervisors and professionals and monitors who are supposed to check rely on reports and papers and walk

*Speaking for Ourselves is an advocacy group whose members are or have been clients of the mental retardation service system in Pennsylvania.

through inspections instead of really coming to see, sharing the food, spending the night.

No one to share the person's life & ask why things aren't better

- Things get worse if there is no one to notice when something isn't working, no one to ask "Why?", no one to figure out what are the right questions to ask, no one to see things from the person's point of view and try to know how it feels. But it's hard to know how things feel when you only have forms and check lists.

No real alternatives

- If there are no real alternatives for a person, procedures for recourse can't work very well. If someone needs another place to live and that other place isn't available, an appeals process can just be hollow.

Problems with service staff

❒ In addition to outright dehumanization, abuse or neglect, many people with disabilities depend on staff people who just don't do their jobs very well.

- Many staff don't seem to understand people with disabilities as people. Maybe this is made worse by trying to improve service by reducing what it takes to care for a whole person into a list of rules and procedures and teams.

Disrespect & lack of understanding

- Many staff are not respectful of the people they look after. They act as if people with disabilities should be grateful and cooperative with anything that gets done. Maybe this reflects social values that assign people with disabilities to second class status.

Ignoring capacities

- Many staff don't pay attention to people's abilities; they just focus on deficiencies. Maybe this reflects social values on verbal intellectual skills and physical ability that overshadow the contributions of people who are not obviously smart or typically skilled.

Lack of cooperative effort among helpers

- Many times the staff people who need to cooperate in order to do a good job can't get it together. They may have meetings between the day and residential staff or between parents and school, but the meetings don't always result in collaborative work on what's best for the person. Maybe this reflects a social myth of self-sufficiency and individualism that makes people who obviously need others to cooperate seem threatening.

Disconnection from community

- Many times staff people talk about integration without seeming to know much about where the mainstream really is or how, in a practical way, to help people with disabilities be more a part of things. Maybe this mirrors the lack of social consensus on the inclusion of people with disabilities. Maybe it also reflects social confusion about what it means for anyone to be an active citizen in our complex, conflict ridden world.

Problems finding a balance between neglect & overprotection

❒ It is very hard to get the right balance of protection for people. On one side lies denial of the person's disability and a lack of necessary support and supervision. On the other side lies a level of excess protection that overshadows opportunities to grow more responsible for self and participate in life. The more individualized the support for a person, the more likely it is that a balance can be found. Group situations make a good balance between too many choices and too few choices almost impossible to find.

Avoidance & denial of problems

❒ Finding out about the hurtful things that are harder to see can be difficult. Many times the person with a disability knows something is needed and missing, but no one who can do anything about it will listen. Sometimes the person with a disability doesn't even know something that would help exists and couldn't ask for it even if someone would listen. Environments that encourage people in power to **listen** to people with disabilities and give people with disabilities **information** and effective **control** will be safer places than those that keep people with disabilities in the dark and decide everything for them

Failure to listen and look

Personal characteristics

❒ Some people with disabilities are especially vulnerable. A person's situation needs careful attention if...

...the person causes trouble and acts uncooperative

...the person has difficulty communicating

...the person seems especially fragile

...the person acts dependent and childlike

...the person does not seem to grow and change much over time

...the person has no real contact with family or friends

...the person does not seem capable of reciprocity in being involved with and contributing to a relationship

Sadly, these are the people that are mostly likely to be grouped together and isolated in the name of "appropriate treatment".

Poverty & social marginality

❒ The line of vulnerability lies at the perimeter of our society. The more people are seen to be different, the harder they will seem to be to understand, the more likely they are to being grouped together, and the more difficult it will be for them to gain control of the resources they need. In stable times, fewer people are pushed over the edge and defined as "them". But the line can shift quickly in times of basic social change. And conditions can grow worse for people pushed outside the edges as uncertainty and a sense of scarcity increase.

Under these conditions, efforts by people on the other side of the line to change things will seem especially threatening to people inside the social perimeter.

Medicalization of basic needs

- A great deal of what people with developmental disabilities need is paid for as a medical expense. Some of this makes sense (e.g. basic health care and some appliances); much of it makes little or no sense (e.g. personal assistants or homes paid for by Medicaid). Much of the rest is for special education expenditures and for rehabilitation. Our investments in people with disabilities don't flow from a concern for the welfare of all citizens; rather they flow from a concern to provide for the special needs of well defined, deserving groups.

Belief that people with disabilities are of less worth

- Our society spends a great deal on medical care. And we have not found ways to limit the application of high technology, high cost procedures. Within limited resources we spend most on heroic treatments in people's last days. But it's easier for policy makers to identify with high tech treatments for "all of us" (who can afford them) than it is to attend to the kinds of basic help people with disabilities need. In this context, some people see competition between the ongoing needs of a relatively few of "them" ("the disabled"), and the acute needs of "all of us". And in this competition, it's easy for policy makers to choose in favor of what they call "the greater good for the greater number."

Belief that meeting the needs of people with disabilities takes away from "us" in favor of "them"

- A similar competition can dominate thinking about education and even rehabilitation services. Many people still think in terms of "educability" and "feasibility for rehabilitation" — categories that keep alive the sense of opposition between people who are more worthy of assistance and less worthy.

Getting left out of decisions about scarce resources

- We have to discover how to decide things our ancestors never had to face. There is more and more discussion about the ethics of such decisions. But people with disabilities are poorly represented in such discussions and ethics experts are often as isolated from people with disabilities and as prejudiced against "them" as anyone else. People with disabilities need to watch and participate in these discussions about ethics, because conclusions about ethics can justify institutionalized neglect and abuse. The discussions are necessary; the issues won't go away. But we have to be active. Some policy discussions to get involved with include:

  - Rationing access to medical care.

  - Justifying euthanasia as a medical treatment.

- Focus on "wellness" and "prevention", especially when images of wellness do not explicitly include the possibility of disabled as a valued way to be a whole person.

- Merging the distinction between human and non-human species in a concern for animal rights.

- Distinctions that divide humanity into persons and non-persons.

• We have to organize with other (potentially) vulnerable groups, including people with physical disabilities and people who are growing older to understand and confront these basic shifts.

Simplistic thinking & going for quick fixes

❒ It's hard to face the facts about abuse and neglect. It's easier to think about things in black and white terms. A simple idea that "institution = bad and community = good" is misleading. There are hard things to get down to the deep parts of. For example...

...we are rightly concerned to offer more and better support to families. But we have to remember that some families are abusive and neglectful.

...we are rightly concerned to move people to smaller living environments. But we have to remember that some such places become abusive and neglectful.

...there is a growing awareness of —if not an increased incidence of— sexual abuse of people with disabilities in all sorts of settings.

...many thoughtful people see current social conditions leading directly to the destruction of people with disabilities. We have to face the hard possibility that the trend toward infanticide and euthanasia may well be rising rapidly and not avoid this harsh reality with efforts to fine tune service systems.

In such situations we need to face the problems that do occur and look carefully at the different variables that create them: Why this family? Why this person? Why this setting? And we need to keep trying to identify ways to detect abuse that don't destroy what's good and finding ways to create healthy environments. We can't assume that the usual solutions —more money, more staff, more rules— are necessarily based on the right understanding of the problem.

Ignoring potential allies

❒ There is another form of oversimplification that makes it hard to manage the issues arising from recognition of the vulnerability of people with disabilities. It's easy to define social values as simply negative and in need of change before any progress can be made. But it's not that simple.

- Many people recognize the injustices done people with disabilities and sometimes will join to fight it.
- Many people are willing to welcome individual people with disabilities.
- Many people believe that, as one participant said, "God put us all here to take care of each other."

Contradictions in good intentions

- But there are contradictions even within positive values. Religious concern can grow out of a sense of "dignity for full human beings/charity for the weak." This can set up a distinction between "providers" and "needers" that undermines community.

Lack of awareness of the history of people with disabilities

❒ People are vulnerable when they have no history. The dark realities of the history of people with disabilities aren't yet completely written. It's too easy to forget that people with disabilities get locked up, they get kicked around, they get put into ice packs, they get ECT and painful shocks as punishments, they get put in cages. And what is written isn't widely known. Children are beginning to learn something of the history of race and gender oppression, but they don't yet learn about the history of people with disability. Better understanding this history would increase a sense of rights for all, build recognition of the problems inherent in institutionalization as a response to people's needs, show us some models of living well despite discrimination, and make everyone more sober about the long term effects of efforts to reform complex situations.

What Keeps Joanie Safe?

David B. Schwartz

It now seemed that Joanie Davis was not destined to end her life in an institution after all. Joanie had been taken to the Willowbrook State School for the Mentally Retarded as an infant, and there she had spent all of her young life. Willowbrook: after the expose, a name synonymous with horror and neglect. Where Geraldo Rivera had taken his television cameras and shown all, except for the stench, on the evening news. Where Governor Hugh Carey, living up to a campaign promise, could be seen in a television scene I still remember brushing the flies from the face of a child in a crib. Where no one ever left. Yet here Joanie was with me with her suitcase and ever-present smile, moving into a nice house on an ordinary street in a small upstate New York city. She, who never had control of her own life, who had been moved from ward to ward and finally to a "family care" home was moving in with us.

Joanie was living under the protection of one of the most sophisticated systems of safeguards of any person with the label of mental retardation in America.

Joanie got to move because of a large and complex lawsuit against the state. Spurred by the Willowbrook expose and other changes, a shift in social policy was phasing down the institutions and making the creation of group homes possible. We had started a group home, and we were welcoming Joanie into it. We said to her, as I did to all new people in those early days, that this was her home and would be as long as she wanted it to be. The board of directors sent her a plant for her room. They were the first flowers that she had ever received. She was, as far as we were concerned, finally home. Another in a series of battered institutional veterans had been taken in to our shelter and attention.

Some people adapt their basic natures to extremely adverse conditions by becoming withdrawn, or aggressive. Some, like Joanie, become especially friendly and likable, cultivating the affection of those in charge. It was easy to try to help her by taking her to one of the physicians in town that we trusted and getting a complete look at her physical condition. For it was clear that Joanie needed serious attention. Tiny; about four feet ten, Joanie walked with a stiff jerky shuffle that made her seem like her leg-joints were fused. She had chronic high blood pressure and was on a lot of medication to control it. Most apparent of all, Joanie had a terribly unsightly skin condition that caused her skin to be constantly flaking off in a kind of fish-scale pattern. We got her the best of attention, and it helped a little. People tended to be put off by her skin condition, but Joanie was so lovable and outgoing that she soon overcame most people's reluctance.

Joanie did so well over the years that she progressed more and more. I heard, long after I had left the agency that I had founded, that she was now living in an apartment with a roommate as she no longer needed the supervision and assistance of the group home. She and her roommate cooked their own meals with periodic help. She went to work every day at the sheltered workshop, and went to activities all over town. She grew to know her neighbors, and became accepted in the neighborhood. It was a long way from Willowbrook.

Almost ten years after I had met Joanie, I was back in town teaching a workshop in group home management at the university. Some of the present-day staff of my old agency took the course. During a break, one of them told me an upsetting story. She had been the person who had had the most recent responsibility for supporting Joanie in her apartment, taking her shopping, helping her with her money, and being on call for emergencies. And Joanie had had an emergency. She started to have kidney failure.

The multiple effects our answers to people's vulnerability show most clearly when traced through one person's biography.

After testing, it turned out that all of those years of having untreated high blood pressure at Willowbrook had done ineradicable damage. She was losing kidney function, and would die if she did not get dialysis treatments regularly. There was yet no dialysis unit in town. (This I knew, for people in that city had to drive an hour and a quarter to the nearest medical center for it.) But instead of arranging transportation to this medical center, or arranging for her to be temporarily hospitalized or cared for in that city and then come home, the state office charged with the welfare of former inhabitants of Willowbrook made a significant decision. They ordered Joanie's transfer to the nearest large state institution for the mentally retarded. There Joanie, once a regular neighbor in a normal neighborhood, was put into a bed on a ward for people with the most severe disabilities. After so many years out, she was back as an institutional resident, and very ill. My promise of a permanent home was an empty one. It was the promise of a person who was no longer there.

Yet when Joanie was "disappeared" from her new home community, when this woman without family or real friends was taken back into the institution the only person who raised her voice in protest was the person who had the closest personal relationship with her.

The young staff member who told me this story was upset. She had thought that it was terribly wrong to put Joanie back in an institution, to give up her apartment forever. She thought it was wrong of the state office that was supposed to look out for her to send her away instead just because she was so ill and needed medical treatment. State institutions were not where you or I would go for medical treatment. This had to be heartbreaking for Joanie, she worried. She tried to get the agency that ran group homes and apartments where she worked to tell the state no. But she had found no support. Instead she had been told by the director of residential services that her advocacy was "threatening to get in the way" of her work and, if it continued, that it would be reflected in her next performance appraisal.

Her story prompted me to break my rule about meddling in my old agency's affairs, on Joanie's behalf, with only very limited success and at the necessary cost of good will. But it made me think deeply about the question of what was supposed to keep people safe in our mental retardation service systems, and in our world. For I had heard very many stories like Joanie's. This one was particularly compelling, however, for Joanie was living under the protection of one of the most sophisticated systems of safeguards of any person with the label of mental retardation in America. She lived in a residential service with internal monitoring. The residential agency was monitored by the quality assurance division of the state office of mental retardation with such particularistic rigor that if their reviewers found on a site visit that a resident's bedroom did not have a chair that a signed waiver that he or she did not want a chair had to be maintained on file in the residence office.

Joanie too had a case manager with the local office of the state office of mental retardation. Because she was a past inhabitant of Willowbrook, this office was required to keep her under specific scrutiny and report her progress to a central office charged with overseeing members of her legal "class." She lived in the state with the most powerful independent oversight agency in the United States, the Quality of Care Commission for the Mentally Retarded. She was served by four separate service organizations. Yet when Joanie was "disappeared" from her new home community, when this woman without family or real friends was taken back into the institution the only person who raised her voice in protest was the person who had the closest personal relationship with her. Under the most complex monitoring system available, the greatest wrong had been perpetrated upon Joanie Davis. The system for keeping Joanie Davis safe had not kept her safe at all. How could the system have failed?

How Regulatory Control Expands

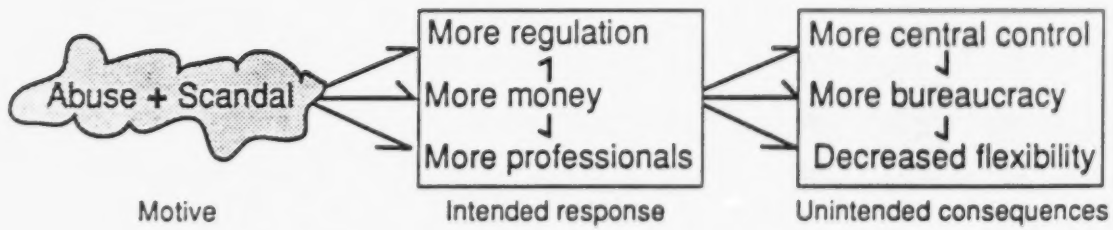
David B. Schwartz

There is no more eloquent description of the process by which regulatory control expands in a democracy than that made by Alexis de Tocqueville in 1835 in *Democracy in America*.

> It frequently happens that the members of the community promote the influence of the central power without intending to. Democratic eras are periods of experiment, innovation, and adventure. There is always a multitude of men [sic] engaged in difficult or novel undertakings, which they follow by themselves without shackling themselves to their fellows. Such persons will admit, as a general principle, that the public authority ought not to interfere in private concerns; but, by an exception to that rule, each of them craves its assistance in the particular concern on which he is engaged and seeks to draw upon the influence of the government for his own benefit, although he would restrict it on all other occasions. If a large number of men [sic] applies this particular exemption to a great variety of different purposes, the sphere of the central power extends itself imperceptibly in all directions, although everyone wishes it to be circumscribed.

Lessons

- Regulation and hence government control over settings in which people with disabilities are found will always expand over time, even if individual government officials at particular times desire to limit it.
- Each incident or scandal, or pattern of incidents, is likely to precipitate an expansion of regulatory control as a method of trying to keep whatever bad thing has happened from happening again.
- The "passions of individuals," most potently expressed through voluntary advocacy organizations, will unwittingly prompt the expansion of governmental regulatory control through attempts to protect those whom they represent.
- The expansion of control will, by formalizing and increasing paperwork and related practices, increase the weight under which formalized caregivers must operate, at the cost of individual and organizational vitality.
- The professionalization of relationships with people with disabilities will increase. The authority of bureaucracies will increase, and the power of citizens will conversely diminish.



Contrasting Approaches

Selecting reasonable action to increase people's security implies more than a choice of tactics. Two different approaches require consideration. The following pages contrast their contribution and limitations in making and keeping people safe and identify their different costs and the factors which contribute to increasing their effectiveness.

One approach, which we called Administrative Regulation & Related Legal Advocacy, formalizes the relationship between people with disabilities and those who provide assistance to them. This approach codifies expectations in statute, regulation, and policy, or –if these fail– in judicial decree. The system values compliance and rationally planned improvement in standard and practice. Judgements about the adequacy of response belong to professionals, with a variety of due process mechanisms to resolve conflicts.

The second approach, which we called Lifesharing & Other Personal Commitments, calls for and relies on personal commitment. People choose to build intentional community or protective relationships with one another. People value the struggle to live creatively in fidelity to the spirit of their commitments. Judgements about quality of shared life depend on mutual trust and listening among those who share a commitment.

Each approach offers something different; but the two mix poorly. Compliance undermines the spirit of commitment. Fidelity depends on trust and breaks down without personal identification and shared values.

There is more than a small touch of irony that today so many people perceive the regulation of the system as the problem. A few short years ago, advocates decried the absence of adequate regulation –a condition that permitted, and still permits, serious abuses of humans to occur under the guise of treatment. The widely publicized nursing home scandals of the early 70's brought about a strong regulatory response. As medicaid became a more important funding source in the mental retardation system, those regulatory responses were lifted and transferred to this system without adequate consideration of their appropriateness or the systems ability to enforce those expectations. Like Topsy, they "just growed." Soon these regulations became the model for other, non-medicaid programs in the system.

–Clarence Sundram

Administrative Regulation & Related Legal Advocacy

Contributions	Limits
✓ Allows rapid change. Some things can be done "with the stroke of a pen".	■ Adversarial relationships, necessary for proper procedure, may harden, pushing apart people who need to work together to achieve results.
✓ Permits broad, uniform movements in policy.	■ Regulations are infrequently written by those most effected. The people closest to the situation typically have to rely on others who are experts in procedures to speak for them.
✓ Can send strong signals about system direction.	■ Regulations limit flexibility —and provide an excuse for inflexibility. There is limited allowance for difference in individual situations.
✓ Can shape the common sense of what is unacceptable.	■ Regulations can be used on people with disabilities to maintain and extend the power others hold over them. They can be used to justify practices that are against the best interests of a person with a disability.
✓ Can shape the common sense of what is possible and desirable.	■ Regulations are often very hard for people with disabilities to understand.
✓ Can clarify what is in people's best interest.	■ Regulations can say different things about how people with disabilities should be treated depending on how the place they live is paid for. This can be confusing.
✓ Does not require waiting for public attitudes to change.	■ Procedures for insuring fairness can get complicated and take a very long time.
✓ Offers public debate of difficult questions; can improve understanding by insuring that different points of view are heard and assumptions and conclusions are challenged.	■ Because regulations have to take account of the interests of several different groups, they can represent a compromise on what would be best for people with disabilities. They can represent what the regulators think they can get people to do rather than what they think is best. This mixes up signals in the system.
✓ Offers leverage to increase vulnerable people's power to seek fair treatment in specific situations.	■ Regulations can be hard to change, even when people agree they don't work well.
✓ Can be used as a way to push new issues or start new initiatives.	■ Money isn't necessarily attached to regulations. Providers can be asked to do things without enough money to do them. And providers that don't live up to regulations can still go on getting money and keeping people.
✓ Offers a way to bring people to the table to negotiate with one another.	■ There are things that are important for people with disabilities that others can't be required to do.
✓ Encourages people that something can be done; that progress is being made.	■ Changes in words in regulations can make some people think that things are really different for people with disabilities. This isn't always true.

Costs	What contributes to effectiveness?
▼ Regulations can drive up money expenditures without necessarily making people with disabilities very much better off.	→ Insure periodic review that accounts the positive and negative effects on people. Look for negative longer term effects that build up over time. Look for unintended consequences.
▼ Regulations and plans developed to respond to unjust treatment of one class of people may lead the system to ignore the needs of people not protected by such designations. This fragments the system more.	→ Increase control of regulations by consumers. At least support the active involvement of consumer groups in negotiating regulations. This support may include helping people learn the skills they need to influence the regulatory process.
▼ Regulations can build up animosity and separateness.	→ Time limit regulations to insure that they are renegotiated regularly.
▼ It is hard for system managers and advocates to openly acknowledge the limits of regulation when it defines so much of their work and when it is one of the main tools available to manage a complex system.	→ Involve consumers and people close to them in reviewing draft regulations to ask exactly what they should expect from regulations and to identify possible problems. This purchases more thoughtfulness and improved foresight at the cost of making regulatory changes take longer.
	→ Look for ways to regulate that support individualization and innovation.
	→ Make tests of parallel systems such as peer review instead of regulatory compliance

Lifesharing & Other Personal Commitments

Contributions	Limits
✓ Answers the fundamental human need for committed, freely given relationships and for community of support and effort.	▮ Can't be done for masses of people.
✓ Complements each individual's gifts.	▮ Grows slowly in terms of the number of people included.
✓ Raises basic question — "Why are we here?" — for every member and provides the place for people to look for the answer with others who share the search.	▮ Relationships develop over time. There are lots of ups and downs. There are disappointments and sorrows as well as achievements and joys. Lifesharing is not a "fix" for suffering, but a way to acknowledge and share suffering.
✓ Not necessarily dependent on human service funds.	▮ There are limits to what people can do for each other within relationships of equality and friendship.
✓ Offers natural ways for people to meet and support one another without professional/client roles intervening.	▮ Doing away with professional/client distinctions doesn't resolve issues of authority.
	▮ There are very powerful social forces against lifesharing. It contradicts many common beliefs and practices.
	▮ People do break personal commitments.
	▮ There are some people lifesharing doesn't suit.
	▮ Some people may face developmental challenges that they can only work out outside close community.
	▮ Abuse is possible in lifesharing situations.
	▮ Lifesharing arrangements look fragile.
	▮ Lifesharing could become a fad.

Costs	What contributes to effectiveness?
▼ The intimacy of living together communally is threatening to many people.	→ More people to live voluntarily in intentional community, including people with positions in managing the service system.
▼ Some people need substantial help, some of which costs extra money.	→ Maintain the space lifesharing needs to grow by respecting its limits and not expecting it to take over for large numbers of people.
▼ People sacrifice some privacy.	→ Avoid the temptation to present lifesharing as a fix.
▼ Commitments limit people's autonomy and options.	
▼ People face uncertainty and fear about "not fixing" difficult situations.	

Competing Social Tools

John McKnight

The associations of community represent unique social tools that are unlike the social tool represented by a managed institution. For example, the structure of institutions is a design established to create *control* of people. On the other hand, the structure of associations is the result of people acting through *consent*. It is critical that we distinguish between these two motive forces because there are many goals that can only be fulfilled through consent, and these are often goals that will be impossible to achieve through a production system designed to control.

The community environment is constructed around the recognition of fallibility rather than the ideal. Most institutions, on the other hand, are designed with a vision imagining a structure where things can be done right, a kind of orderly perfection achieved and the ablest dominate....

In the proliferation of community associations, there is room for many leaders and the development of leadership capacity among many. This democratic opportunity structure assumes that the best idea is the sum of the knowings of the collected fallible people who are citizens. Indeed, it is the marvel of the democratic ideal that people of every fallibility are citizens. Effective associational life incorporates all of those fallibilities and reveals the unique intelligence of community.

Institutions, on the other hand, have great difficulty developing programs or activities that recognize the unique characteristics of each individual. Therefore, associations represent unusual tools for creating "hand-tailored" responses to those who may be in special need or have unique fallibilities. Our institutions are constantly reforming and reorganizing themselves in an effort to create or allow relationships that can be characterized as "care." Nonetheless, their ministrations consistently commodify themselves and become a service.

Why is it, then, that social policy so often ignores community? One reason is that there are many institutional leaders who simply do not believe in the capacities of communities. They often see communities as collections of parochial, inexpert, uninformed and biased people. Indeed, there are many leaders of service systems who believe that they are in direct competition with communities for the power to correctly define problems, provide scientific solutions and professional services.

In this competitive understanding, the institutional leaders are correct. Whenever hierarchical systems become more powerful than the community, we see the flow of authority, resources, skills, dollars, legitimacy, and capacities away from communities to service systems. In fact, institutionalized systems grow at the expense of communities. As institutions gain power, communities lose their potency and the consent of community is replaced by the service of systems; the citizens of community are replaced by the clients and consumers of institutional products.

Three visions: Therapeutic Advocacy Community

As one observes this struggle, there appear to be three visions of society that dominate the discourse.

- The first is the **therapeutic vision**. This prospect sees the well-being of individuals as growing from an environment composed of professionals and their services. It envisions a world where there is a professional to meet every need, and the fee to secure each professional service is a right. This vision is epigrammatically expressed by those who see the ultimate liberty as the "right to treatment."
- The second prospect is the **advocacy vision**. This approach foresees a world in which labelled people will be in an environment protected by advocates and advocacy groups. It conceives an individual whose world is guarded by legal advocates, support people, self-help groups, job developers, and housing locaters. Unlike the therapeutic

"The surest indication of the experience of community is the explicit common knowledge of tragedy, death, and suffering. The managed, ordered, technical vision embodied in professional and institutional systems leaves no space for tragedy. They are basically methods for production and have no room for tragedy. Indeed, they are designed to deny the central dilemmas of life."

vision, the advocacy approach conceives a defensive wall of helpers to protect an individual against an alien community. It seeks to insure a person's right to be a functioning individual.

- The third approach is the **community vision**. It sees the goal as "recommunalization" of exiled and labelled individuals. It understands the community as the basic context for enabling people to contribute their gifts. It sees community associations as contexts to create and locate jobs, provide opportunities for recreation and multiple friendships and to become the political defender of the right of labelled people to be free from exile.

Those who seek to institute the community vision believe that beyond therapy and advocacy is the constellation of community associations — the church, the bowling league, the garden club, the town paper, the American Legion, the hardware store and the township board. They see a society where those who were once labelled, exiled, treated, counseled, advised and protected are, instead, incorporated in community where their contributions, capacities, gifts and fallibilities will allow a network of relationships involving work, recreation, friendship, support and the political power of being a citizen....

The informality of community is expressed through relationships that are not managed. Communities viewed by those who only understand managed experiences and relationships appear to be disordered, messy, and inefficient. What these people fail to understand is that there is a hidden order to community groups that is determined by the need to incorporate capacity and fallibility.

While institutions and professionals war against human fallibility by trying to replace it, cure it, or disregard it, communities are proliferations of associations that multiply until they incorporate both the capacities and the fallibilities of citizens. It is for this reason that labelled people are not out of place in community because they all have capacities and only their fallibilities are unusual....

Professionals and institutions often threaten the stories of community by urging community people to count up things rather than communicate. Successful community associations resist efforts to impose the foreign language of studies and reports because it is a tongue that ignores their own capacities and insights. Whenever communities come to believe that their common knowledge is illegitimate, they lose their power and professionals and systems rapidly invade their social place.

The surest indication of the experience of community is the explicit common knowledge of tragedy, death, and suffering. The managed, ordered, technical vision embodied in professional and institutional systems leaves no space for tragedy. They are basically methods for production and have no room for tragedy. Indeed, they are designed to deny the central dilemmas of life. Therefore, our managed systems gladly give communities the real dilemmas of the human condition. There is no competition here. Therefore, to be in community is to be an active part of the consolation of associations and self-help groups. To be in community is to be a part of ritual, lamentation, and celebration of our fallibility.

From: Regenerating Community (1987).

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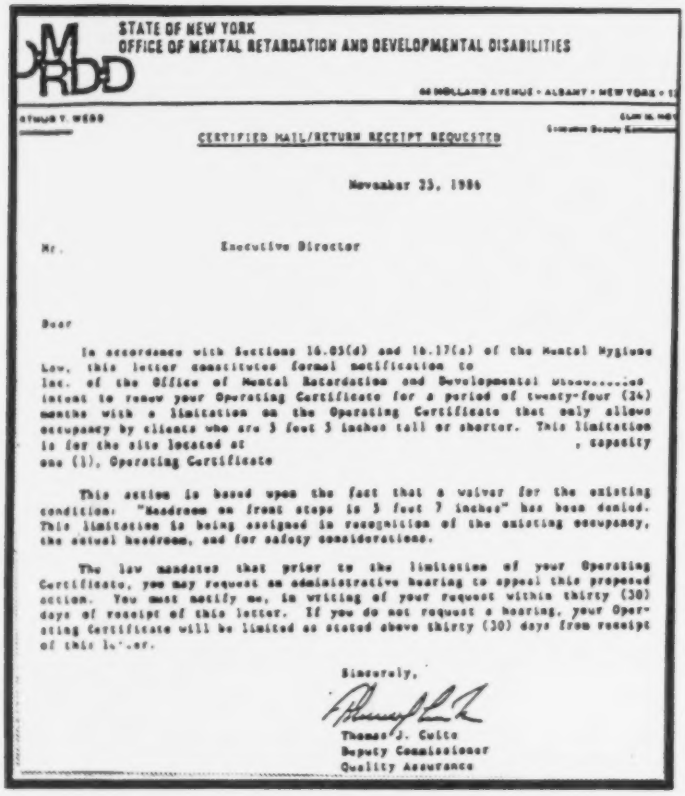

STATE OF NEW YORK
OFFICE OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

44 HOLLAND AVENUE • ALBANY • NEW YORK • 12

CERTIFIED MAIL/RETURN RECEIPT REQUESTED

November 25, 1986

Mr. Executive Director

Dear

In accordance with Sections 16.03(d) and 16.17(a) of the Mental Hygiene Law, this letter constitutes formal notification to Inc. of the Office of Mental Retardation and Developmental Disabilities intent to renew your Operating Certificate for a period of twenty-four (24) months with a limitation on the Operating Certificate that only allows occupancy by clients who are 5 feet 5 inches tall or shorter. This limitation is for the site located at , capacity one (1), Operating Certificate

This action is based upon the fact that a waiver for the existing condition: "Bedroom on front steps is 5 feet 7 inches" has been denied. This limitation is being assigned in recognition of the existing occupancy, the actual headroom, and for safety considerations.

The law mandates that prior to the limitation of your Operating Certificate, you may request an administrative hearing to appeal this proposed action. You must notify me, in writing of your request within thirty (30) days of receipt of this letter. If you do not request a hearing, your Operating Certificate will be limited as stated above thirty (30) days from receipt of this letter.

Sincerely,

Thomas J. Cutts
Deputy Commissioner
Quality Assurance

The Loss of Spirit

David B. Schwartz

Believing that constantly increasing levels of regulation will keep the social environment of vulnerable people safe and healthy is like believing that constantly increasing doses of antibiotics will keep a malnourished child healthy. In its potential for misdirecting attention from deeper issues, it can unwittingly do long term harm to the fabric of human relationships through which human life really works.

Anecdotal evidence that our "caring systems" are suffering under the weight of regulatory paperwork is widespread. One has only to talk to any worker to hear stories of how caring is being displaced by compliance activities which were paradoxically originally installed by system advocates to improve care.

The deterioration of spirit signaled by these anecdotes is the main toxic effect of increased regulatory control. Once we wipe out spirit, we have killed off the heart of the entire enterprise. Caring and idealistic people are drawn to moral enterprises and to people in need. They tend to be driven away from bureaucratic machinery.

One of my friends remains at work despite the rising tide of regulation. A couple of years ago, he helped to set a person up in a little apartment Life for this man flourished. He became known and accepted in the neighborhood, and became a fixture at the corner market. His life, after many years of bloodless warehousing and programming, began to mean something in a social context.

Eventually the inspector from the state office of mental retardation came for a routine certification visit. He inspected the man's apartment and found it substantially in compliance, except for one problem. The back stairway door, the required "second egress" in the code, was too short. People could bang their head running out if there were a fire. This was serious; the apartment would have to be decertified. The man would have to move.

Move? My friend didn't know what to think. But he had worked for the state office himself. He knew a few of the tricks. He tried a weak, ironic joke. He pointed out that in fact this person would never bump his head — he was only 5'5". "Why don't you just give me a waiver of regulations," he asked, "a waiver for short people?"

The waiver was denied, but a creative bureaucrat found a solution. The agency's operating certificate was linited "to only [allow] occupancy by clients who are 5'5" tall or shorter." The man is still there. How long will my friend stay? My guess is not forever. Because every such event probably erodes his ability to maintain commitment to his work.

Strategies for Increasing People's Safety

Work for social change...

- People with disabilities and their families are on the short end of social power. Remedying this means more than just increasing participation in service planning or service delivery. To get to the root of the problem we have to increase the political power and cultural standing of people with disabilities. Any response that simply focuses inside the service system will be incomplete, no matter how desirable it may otherwise be.

- The key theme is keeping people together. Disabled and able together in all life experiences from preschool on up. In work, in recreation, and in all of community life. Making this happen takes caring coaches for both able and disabled people.

"Any response that simply focuses inside the service system will be incomplete."

- We need to make it clear that powerlessness equals abuse. That information, plus support from someone who cares, plus access to effective methods of recourse are the minimums necessary to safety for people with little power and control.

- Personal relationships are an essential part of any system to discover and act on abuse and neglect. People need others to confide in, others to see what's happening for them.

- We need to encourage everyone —starting with ourselves— to inventory our own abilities and disabilities so that we know what we all have to give and so we can start working on the ways that each of us are weak in living well with other people.

- We are talking about increasing symbiosis among people. We need to talk more about humankind and less about people with disabilities as a "special" kind of human.

- We need to find more ways to link the interests of people with disabilities to other community members; for example, through the development of cooperative housing associations.

- We lack a technology for changing attitudes. And some of us think a formula can't ever be found for the kind of change that's needed. But we can set the stage for attitudes to change. We can be sure that people have role models of people with disabilities whose lives are successful.

Support the contribution of families & friends...

- Many people would be sunk without the support and advocacy of their family and friends.
- We have to think carefully and face some hard facts about family life and committed relationships.
  - Lifestyles are changing. Many people have single parents. Many people have both parents working. Living well together takes time and having to advocate continually for necessities takes more time.
  - There can be big differences within families in the extent to which a family member with a disability is valued and accepted as an equally valuable person by other family members.
  - Many families and friends act apathetic —or numb— because even the services that are supposed to help are confusing and very hard to get what a person needs from. Information is hard to find.
  - Not even getting listened to by people whose job is to help can burn you out on trying to ask for things from community members.
  - Families and friends can be abusive and neglectful, especially when they lack support. We have a lot to learn about improving the ability of family and friends to cope.
  - Some families and friends have very limited ideas about the possibilities for a person with a disability (So do many service workers).
  - There is a great deal of talk about families disintegrating. We have to figure out what all this talk means. We can't afford to hope for something that can't happen; but we also can't afford to just pass around a lot of cliches about how bad everything is without checking them out.
- Vouchers for family support and (early) education services could increase access to integrated settings.
- Many families need opportunities to plan seriously about, "What happens when we no longer can provide what out disabled son or daughter needs."
- We need to develop better ways to get information to families in ways that makes sense.
- Families need to know from their child's earliest years how important it is for disabled and non-disabled children to learn with and from each other.

Work on service system issues...

- Lots of people need at least some help from services. But as people with disabilities represent increasing cash value to service providers and service system operators, the incentives grow to find things wrong with people and to keep people dependent. Under these conditions services necessarily must push people with disabilities away from community association. We need to find counterforces to this threat.

- Some people have nobody to count on except a busy case manager, who has too many people and too much paperwork.
  - These people need a buddy to advocate for them instead of having to wait for a case manager to get around to them.
  - Organizations like Speaking for Ourselves* can help if there are ways to meet and organize people who are alone and powerless.
  - Case manager's jobs should be restructured. They should spend enough time to get to know people and check how things really are. Not just short visits, or meetings, or looking at papers, but sharing experiences with people.
  - If this restructuring of case management isn't possible, make it clear to everybody that the case manager is there for the system's paperwork and can't do much to keep people safe or improve things. Otherwise, people will think things are better than they are. And that's dangerous.

- High turnover among direct service staff makes it very hard for staff to know a person well enough to make good judgements about acceptable risks.

- The contradictions between how services are funded and regulated and people's sense of what is right creates a problem. The stronger staff commitment to positive roles and experiences for people, the more likely a conflict with rules and funding patterns. This increases staff frustration which could lead them to quit or withdraw from their work. We need to experiment with alternative ways to monitor and regulate services.

- It's important for writers and enforcers of regulations to see the real effects of their work on what we value in people's lives.

- We need to create windows of opportunity to maintain contact and respectful discussion between people concerned with administration, people concerned with advocacy, and people who are lifesharing. Our discussion shows that each way needs the others; each can contribute to mutual education. All must learn to focus on social and cultural change. It's easy to divide ourselves; we have to work at coming together.

*Speaking for Ourselves is an advocacy group whose members are or have been clients of the mental retardation service system in Pennsylvania.

Support the contribution of service workers...

- Service workers (and regulators) need methods for "role release:" ways to give up some control in favor of people with disabilities and their families.
- Service workers can gain in ability to "walk in people's shoes"; to look at decisions from the point of view of people with disabilities and to appreciate the life experiences that have influenced many people with disabilities.
- Service workers need to clarify and change their own possible contributions to disempowering people through everyday practices and routines.
- Service workers need to practice hearing what people with disabilities have to say.
- Building personal relationships between service workers, family members, and people with disabilities is important.
- It takes a lot of common sense to deal with people in a way that keeps them safe. Education and credentials don't necessarily mean empathy for people.
- Service workers need opportunities to reflect on their work and their commitment to people with disabilities in small, soul searching events.
- Service workers need to reflect on the kinds of educational experiences and back-ups will help people with disabilities make good decisions in risky situations.

Accounting and Reducing the Costs of Regulation

Clarence Sundram

When we regulate not wisely, but too much, we stifle initiative without replacing it with something of higher value. We aim at a common level of undistinguished performance that eliminates both risks of failure and challenges to soar to excellence. We breed an attitude of compliance with regulation rather than reinforcing the sense of mission that draws so many people into this field. And too often, satisfying auditors and regulators becomes the mission rather than caring for the human beings the system was created to serve.

"... too often, satisfying auditors and regulators becomes the mission rather than caring for the human beings the system was created to serve."

These results are understandable given the multiple and conflicting forces pulling and tugging at the employees who are caught in the middle. They have one set of duties that require them to meet almost every dimension of human need of residents of their facilities — a challenge that can well consume every ounce of their energy, skill, and commitment. They have another set of duties to comply with conditions that allow their programs to exist, to remain certified and funded. The regulatory system deals little or not at all with the first set of responsibilities but regularly scrutinizes the latter. Administrators and managers who worry about the external demands on their programs are forced to make sure they comply with regulatory requirements. When only one set of duties is regularly and systematically reviewed and reacted to both internally and externally, it is easy to create a value system that exalts paperwork over care. And, the truth is that often these paper duties may be more seductive because, in many cases, meeting the needs of people can be both physically and emotionally draining. But, over time, the priority for paperwork can have a by-product of eroding initiative and breeding apathy, with mindless tasks that try to measure the immeasurable or the irrelevant, while tasks which nourish and enrich the human spirit go neglected....

Considerations

1. Regulators need to become more conscious of the enormous power they wield and of its great potential to destroy initiative — the very life blood of the system. They need to be careful about the behaviors they reinforce and don't reinforce in regulated programs, and to think more critically about what they want to achieve beyond compliance. In particular, we need to consider whether there are better ways than endless documentation to ensure quality care. Our own experience in monitoring conditions in psychiatric and developmental centers suggests that direct observations by outsiders of a significant part of residents' waking hours provides a reliable barometer of actual performance of many important duties, without reinforcing paperwork duties.

2. Program directors, professionals, direct care staff, parents, advocates — all of us — need to think anew what we want and don't want from a regulatory system and examine more carefully the cost of the choices we make. We cannot guard against all risks all the time without turning both our staff and their charges into automatons.

3. All of us need to consciously reaffirm the paramount value that undergirds the service system — providing care and all that word entails – for people who cannot care for themselves. We need to be strong advocates for these values and resist any activity that encroaches upon this fundamental obligation.

from: Regulation – Have we all gone mad? *Quality of Care*, September-October, 1987 p.7.

We often say, "We must *produce* programs of excellence." Does this not display our fundamental error? For if caring can be produced, if it indeed is a product, then the quality of this product can be regulated. If caring is a resource to be purchased, then the process of helping care arise into the world is a process of production, in which economic and material laws are primary. From such beliefs, the eventual development of regulatory control is inevitable, for it proceeds logically from the same conception of the activity. That is why quality assurance programs in human service are so evocative of industrial quality control programs; the former were patterned directly upon the latter. We believed that we were dealing in both cases with "products."

We must realize that we are confusing two very different approaches to human endeavor. We might think of these approaches as tools. The one, professionalistic and hierarchial, may work well to produce automobiles. The other—informal, relationships based, and oriented to community— is good at caring. Somehow along the way we have gotten the two muddied. We have found ourselves with the wrong tool in our hands. Thinking all problems to be nails, we strenuously hammer away at caring as things get steadily worse.

–David B. Schwartz.

Options for Action

To Make Children Safer

More Powerful Families

→ We need to keep focus on strengthening and informing families with children with developmental disabilities. A child's parent or parents are the key to safety. Grandparents, aunts and uncles matter too. So do brothers and sisters.

→ When children live away from their families, its important to make sure that families are welcomed, involved and listened to. If a child lives away from a family and has no family involvement, it's vital that that child have substitute family members.

Reduced Isolation

→ We need to work on ways to reduce family isolation and children's isolation. Non-disabled school mates and university students have made such a big difference for some of our families. We need more ways to increase the chances that each child with a developmental disability will get a chance to meet "the other people" who can give the gifts of acceptance and participation.

→ We need to strengthen the sense of expectation that all children will be involved with their age peers in school and in recreation. Non-disabled children need to come to expect the presence of children with disabilities. This begins to overcome isolation and reduce the chances of abuse.

→ We need clearer, more detailed ideas about how to get the resources we all rely on to be involved with children with developmental disabilities without smothering them. We need good schooling without all containing special education; we need recreation without isolated special olympics.

More Effective Services

→ How do we encourage the development and employment of more teachers who have the desire, the ability, and the assignment to facilitate the development of relationships between disabled and non-disabled students?

→ We need to increase the range of alternatives available. People with disabilities are more vulnerable when they are uncooperative. They are more uncooperative when they are trapped in a situation that doesn't work for them. Most of the time there is only one situation possible. This increases the chances of a person getting trapped.

→ There need to be clear avenues of recourse for people in every program, no matter what its type. We need to insure that someone who is in a dangerous situation has a way to let someone outside the setting know if there is a problem.

→ We have to work systematically on the essential issue: changing attitudes and expectations about the place of people with developmental disabilities in their their lives, in our communities, and in society. This essential work begins with our own personal relationships with people with developmental disabilities and our own active involvement with our fellow citizens in the life of our own communities.

→ This kind of social change moves slowly, from person to person in social networks. This means keeping a long term perspective on our policies and investments. People with developmental disabilities will be safer as more other citizens become personally involved with them.

→ We need to continue learning about what it takes to build and strengthen personal relationships and social involvements for those people with developmental disabilities who would otherwise be isolated.

- The best way to learn about this is through investments in local people's efforts.
- We should support a variety of efforts to be sure that communities have people who will be there to ask for and support personal involvements.
- As this body of experience grows from projects focused on assisting people to become part of community life, we need to invest in communicating their lessons and sharing their tools.

→ We need to help systems explore more ways to put power, money, rulemaking, and monitoring in the hands of people with developmental disabilities and those people closest to them.

- The system we have now generates increasingly detailed rules within a system that institutionalizes major inequalities and disempowers people. We need to experiment with major changes in these systemic ways of keeping people unequal and without the resources to stand up for themselves.

- Just offering more of what we have now can't work to give people the power they need to be safer. But demand on the system —from people who have little or no help now or from advocates for people who are especially and obviously hurt by the worst of current services— means big pressure for more. We need to focus influence and money on efforts to create windows for action to make the system different.

- There is much to learn about alternative ways to help people with developmental disabilities and the people closest to them to see, understand, and respond to the real risks in people's lives.

→ We need to face and explore the possibility that our social systems, including our service systems are collapsing. Many people have not considered this possibility and some people who have think it unlikely. But a number of thoughtful people associated with the council believe this is already happening, though they may not see the same causes or predict the same consequences. We need to find ways to assess this possibility (some would say, certainty) and help people explore the role of citizens in a collapsing situation.

Minimizing the costs of regulation

→ Understanding and achieving a balance of risk and safety is complex.

- Risk can come from strangers or outsiders, but it can also come from people you know and rely on such as service staff or family members. It would be easier to deal with this issue if all risk came from "outsiders" or if we could be confident that family and friends or professionals very seldom posed a significant risk.

- There is a theory that people are safer in community settings, which are more open, than in institutional settings, which are more closed. But what does "openness" mean? Does "openness" mean having lots of government inspectors visiting? How can a place be "open" and still be private? Does "openness" mean that a person has lots of friends visiting? If so, just locating people in small houses doesn't automatically mean they are in an open environment.

- Regulation can contribute to people's safety by insuring that sufficient authority is available to deal with bad situations. But regulation can make balance hard to achieve. It's very hard to develop regulations that are both powerful enough to rescue people from abuse and subtle enough to support people striving for balance.

- The idea of "the dignity of risk" is a valuable corrective to the tendency to overprotect and over regulate. But it doesn't provide much guidance for knowing when to choose for safety.

→ We need to do some hard thinking to place this issue in the context of larger social trends. Over the long term, demand on human service systems will continue to rise rapidly as other large scale social changes make strong demands for new ways to organize and manage. Formal systems will get more fragile and more erratic.

→ We need to ask what we can do now to shape an environment that promotes the development of alternatives to widening the existing regulatory stream